

CADASIL - CADASIL patient cohort

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General

Identification

Detailed name CADASIL patient cohort

Sign or acronym CADASIL

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation Accord CNIL

General Aspects

Medical area Neurology

Health determinants Occupation

Keywords cognitive decline, mobility impairment, migraine, ischaemic stroke, epileptic seizure, Health episodes, apathy, hospitalisation, health system

Scientific investigator(s) (Contact)

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Organization APHP

Collaborations

Funding

Funding status Mixed

Details PHRC, Centre de maladies rares, dons association ARNEVA, Association CADASIL France (familles)

Governance of the database

Sponsor(s) or organisation(s) responsible APHP

Organisation status Public

Additional contact

Main features

Type of database

Type of database Study databases

Study databases (details) Cohort study

Database recruitment is carried out by an intermediary A selection of health institutions and services

Database recruitment is carried out as part of an interventional study No

Database objective

Main objective General objective: prospective study of patients with Notch 3 gene mutation thought to cause CADASIL: research into prognostic factors and useful markers for preventative treatment trial. Secondary objectives: - To determine clinical-radiological correlations - Modifying factors of clinical phenotype and MRI studies - Prognostic and progressive factors - Clinical phenotype variability - Natural history of disease

Inclusion criteria Adult patients with Notch 3 genetic mutation thought to cause CADASIL

Population type

Age Great age (80 years and more)

Population covered Sick population

Gender	Male Woman
Geography area	Local
French regions covered by the database	Île-de-France
Detail of the geography area	Lariboisière Hospital, Paris
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	04/2006
Date of last collection (YYYY or MM/YYYY)	12/2007
Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	250
Data	
Database activity	Data collection completed
Type of data collected	Clinical data Paraclinical data Biological data
Clinical data (detail)	Medical registration
Paraclinical data (detail)	Carotid Doppler ultrasound and MRI with measurement or calculation of total lacunar infarcts and white matter hyperintensities, brain volume, average circulation and number of microbleeds
Biological data (detail)	Biological assessment
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	

Participant monitoring	Yes
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Links to administrative sources	No
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Promotion and access

Promotion

Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=CADASIL+AND+cohort+AND+apathy+AND+Chabriat+H[Author]
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Description	List of publications in Pubmed
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Access

Terms of data access (charter for data provision, format of data, availability delay)	To be decided by scientist in charge
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Access to aggregated data	Access on specific project only
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Access to individual data	Access on specific project only
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